DOCUMENT RESUME

ED 166 918 EC 113 708

AUTHOR	Barrows, Howard S.; Goldensohn, Eli S.
TITLE	Guide for Parents.
PUB DATE	[78]
NOTE	20p.
AVAILABLE FROM	Ayerst Laboratories, 685 3rd Avenue, New York, New York 10017 (Free)
EDRS PRICE	MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS	*Clinical Diagnosis; *Epilepsy; Etiology; *Medical Treatment; Seizures
IDENTIFIERS	Parent Resources

ABSTRACT

Intended for parents of children with seizures, the booklet provides information on etiology, treatment, diagnosis and management of epilepsy. The following topics are briefly discussed: why seizures occur, factors that may increase the frequency of seizures, types of seizures, ways to protect the child from accidental injury, and future considerations. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Guide for Parents

ED166918

U S DEPARTMENT OF HEALTH
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

EC 11 3708

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

E. Goldenshohn

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC) AND USERS OF THE ERIC SYSTEM."

by
Howard S. Barrows, M.D.
Professor of Medicine (Neurology),
McMaster University
Hamilton, Ontario
and
Eli S. Goldensohn, M.D.
Professor of Neurology,
Columbia University
Attending Neurologist,
Neurological Institute,
Presbyterian Hospital
Director of Seizure Clinic,
Vanderbilt Clinic,
Presbyterian Hospital, New York

3

Introduction

It is natural for parents of a child with seizures to be seriously concerned. They are confronted with a situation that seems strange and sometimes frightening. In most cases, they know little about seizures, and what knowledge they do have is often based on superstitions derived from the Dark Ages. In addition, half-truths and false information given to them by well-meaning friends and neighbors only add to their anxiety. Medical research has made great advances in the methods of treating seizures and greater advances will certainly be made in the future.

The purpose of this booklet is to explain in simple terms the essential facts concerning seizures and their treatment. It explains how your child may be studied, and how he or she may be treated. It will help you understand the problem you are facing, and show how you and your child can learn to cooperate with your physician. A good working relationship between you and the doctor is essential for the success of your child's treatment.

Distributed as a service to the medical profession by
Ayerst Laboratories, New York, N.Y. 10017.

4

What epilepsy is—and isn't

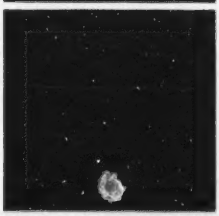
About two million people in the United States have some form of epilepsy.*

It is surprising that so many people have unreasonable and unjustified fears about such a widespread condition. Their fears are the result of knowing little or nothing about the true nature of epilepsy. Unless they learn the correct facts, they can contribute to making the lives of people who suffer from epilepsy miserable.

The word "epilepsy," like many other medical terms, comes from the Greek language and means "seizure." Epilepsy, then, is nothing more than a tendency to have seizures—often called spells, attacks, fits, convulsions, or the "falling" sickness. Epilepsy is not a disease but, rather, a group of symptoms resulting from many different conditions which cause some brain cells to be in a state of excessive irritability. The majority of people with epilepsy are otherwise normal and healthy, with average or above average intelligence. In general, epilepsy does not shorten life and does not cause insanity. Epileptics differ from other people only in their tendency to have seizures. Many prominent people have had epilepsy—including some great political leaders, artists, musicians and scientists. In our own times, there are a number of epileptics whose seizures are well-controlled and who have become successes in their chosen fields.

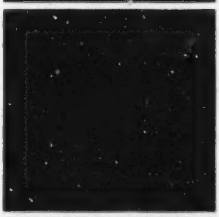
*Commission recommends upgrading epilepsy care, Pediatr. News 11:6 (Nov.) 1977.

SOCRATES

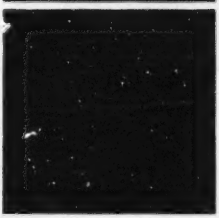


CAESAR

DOSTOEVSKI



LORD BYRON



BERLIOZ

How the brain governs the body

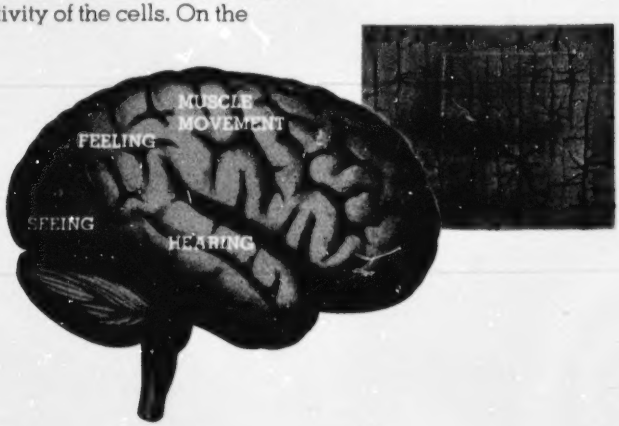
Since seizures originate in the brain, it is helpful to know something about what this organ does and how it works. The human brain regulates and controls what a person does and does not do. It regulates mental processes, emotional reactions, and physical activities. Simple muscular activities such as walking and standing, and more complex activities such as talking, playing a musical instrument, drawing, or writing are all controlled by the brain. Sensations such as seeing, hearing, smelling, tasting, and feeling are received and interpreted in the brain. All mental activities such as thinking, remembering, and using language are performed in the brain. In addition, the brain regulates the inner workings of the body such as the action of the heart, breathing, and digestion.

The brain is a complex and sensitive organ, carefully protected inside the skull. It is far more complex than the largest modern computer, and is made up of many millions of tiny units called cells. To accomplish the brain's many functions, each cell works in smooth harmony with other brain cells and with the cells in all the other parts of the body. In certain areas of the brain, the cells specialize in a specific job. For example, one area is mainly concerned with muscular activities, another mainly with seeing, while others regulate various body functions such as breathing and circulating the blood. Normally, such areas work together in a smooth, well-ordered way.

Why seizures occur

A seizure occurs whenever a group of brain cells becomes overactive, breaking down the well-ordered cooperation within the brain. This overactivity may be confined to one area or it may spread to other areas of the brain. Sometimes the entire brain becomes overactive—usually for a limited period of time. After the seizure ends, harmonious activity is restored among the brain cells. Everyone is capable of having a seizure if certain brain cells are sufficiently overactive. In some children, the brain cells seem to be unusually prone to overactivity. Consequently, they may have seizures spontaneously or from stimuli that would not ordinarily have this effect.

Possible causes of seizures. Why do brain cells suddenly become overactive? Many times the exact cause can never be found. There is often no evidence of previous brain damage or specific nervous disease to account for the overactivity of the cells. On the other hand, seizures may be related to brain damage which occurs before, during, or shortly after birth—times when the brain and skull are often injured. Head injuries occurring after infancy cause seizures in only a small number of children. Many neurological diseases, or infections of the brain or its covering, such as meningitis and encephalitis, may result in seizures. Hereditary factors play a role in some cases. Diseases apparently unrelated to the brain may also cause seizures by greatly reducing the amount of substances like sugar or calcium in the blood which the brain needs in adequate supply to function normally.



Factors that may increase the frequency of seizures

Many factors can provoke seizures in a child who is subject to them. These factors enable seizures to occur more easily because they reduce the resistance of brain cells to overactivity. If they can be avoided, better seizure control may be achieved. The following list contains commonly recognized factors that tend to bring on seizures:

1. Irregular use or reduced dosage of prescribed medication
2. Illnesses of any type, especially those associated with fever
3. Emotional stress
4. Restricted activity and idleness
5. Fatigue and lack of sleep
6. Menstrual periods
7. Exposure to certain visual and auditory stimuli such as rapidly flashing lights or loud music with a heavy beat (rock)

Of all these factors, the most common is failure to take medications precisely as prescribed—such as the irregular use of antiepileptic medication or the reduction of dosage without medical advice.

Types of seizures

What happens to a child during a seizure depends largely on which group of brain cells becomes overactive. Since there are so many areas of the brain controlling different functions, many kinds of seizures are possible. He or she may have only one type of seizure or several types. Many children have sensations called "*auras*," which may consist of strange feelings in the abdomen, spots before the eyes, unusual odors or tastes, past memories, anxiety or tenseness. These auras can provide valuable clues about where the brain cell overactivity originates. For instance, an aura of an unpleasant odor may indicate that the seizure originates in an area of the brain behind the temple. When they precede other types of seizures, auras represent a warning signal that an attack is about to begin. If the child can describe a signal-type aura, or if a parent can recognize it, auras can be very helpful because while they are occurring the child can move or be moved into a position to prevent accidental injury when the full attack occurs.

Petit mal or short absences. These seizures are usually seen in childhood and disappear with the attainment of adulthood. The child has no warning aura and does not fall down. Most people watching think that the child is only staring or daydreaming because the seizure consists of a sudden, brief loss of contact with the environment. During these attacks, the eyes often blink and there may be slight jerking of the arms and legs. After the seizure, the child's mind is clear and he or she can immediately resume usual activity. Petit mal seizures occur many times each day, but each episode lasts only a few seconds. In these seizures, the cells over a wide area on both sides of the brain are overactive.

Grand mal, or generalized major motor seizures. In these seizures, there is overactivity in widespread areas of the brain that maintain consciousness and regulate body movements. Auras may or may not occur. Typically, the child loses consciousness, falls to the ground, and then has a convulsion. All the muscles tighten and there are usually some jerking movements of the arms and legs. The eyes may roll up and the child may turn pale or bluish for a short period. This is followed by deep breathing which may be accompanied by heavy snoring sounds. The child may also wet or soil himself or herself, and bite the tongue or cheeks. The seizure generally lasts a few minutes. Afterwards, the child may be sleepy, confused, exhausted, and complain of a headache, but will have no memory of the seizure itself. When the seizure is over, the child will often fall into a deep sleep.

Psychomotor, or complex partial seizures. In this type, the child performs apparently purposeful movements during the time his consciousness is clouded. He may merely pick at the clothes, or make chewing movements, or perform more complicated acts. Sometimes the child's behavior is strange. He or she may experience auras such as hallucinations, delusions, or changes in mood. The entire attack usually lasts about a minute and is followed by another minute or so of confusion. The child does not remember the seizure. Psychomotor seizures usually, but not always, originate in an area of the brain called the temporal lobe—an area that has complex functions associated with memory, taste, smell, and behavior.

Focal or partial seizures. When cells in one particular area of the brain become overactive, the seizure affects the functions which that area controls or regulates. These are known as either focal or partial seizures. Two types of focal or partial seizures are described:

1. Motor seizures. Overactivity occurs in the part of the brain that controls the mucles of a particular section of the body, causing sudden jerking movements in one area, such as the face, the arm, or the leg. Sometimes the overactivity spreads to adjacent regions of the brain, gradually involving more and more muscles. Focal motor seizures may begin with shaking or jerking of the hand, then the forearm, arm, shoulder, face, progressing in this fashion until the entire half of the body is involved. If the overactivity continues to spread to the entire brain, the focal motor seizure develops into a typical grand mal attack.

2. Sensory seizures. This kind of focal seizure affects the part of the brain concerned with sensations. The child may experience numbness, tingling and coldness, or sometimes have special sensations involving hearing and seeing. If the affected brain area deals, for example, with sensation in the hand, the sensation seems to begin in the hand. If the affected area involves hearing, the seizure begins with sounds that seem to come from nowhere. You can imagine the large number of different focal sensory seizures that can occur, depending on where the brain cell overactivity begins.

How the doctor makes the diagnosis

The doctor makes numerous investigations to find the answers to important questions. What type or types of seizures does the child have? What is the cause of the seizures? How can they best be treated? He seeks the answers by gathering information in many, if not all, of the following areas.

History. The doctor depends heavily on your observations and descriptions of the kind of seizures your child has. Since the doctor rarely has an opportunity to see your child's seizures, your description must be as accurate as possible. He wants to know how the child appears just before, during, and after the attack. How do the seizures start and how do they progress? At what age did they start? In the older child, have seizures worsened around ages 12 to 14? In a menstruating girl, are seizures related to her periods? How severe and frequent are the seizures? Have they changed? Have they been treated before—with what medicines and in what dosages? How effective was the treatment? The doctor needs to know about the child's birth, growth, development, and health—past and present—and about the health of the entire family.

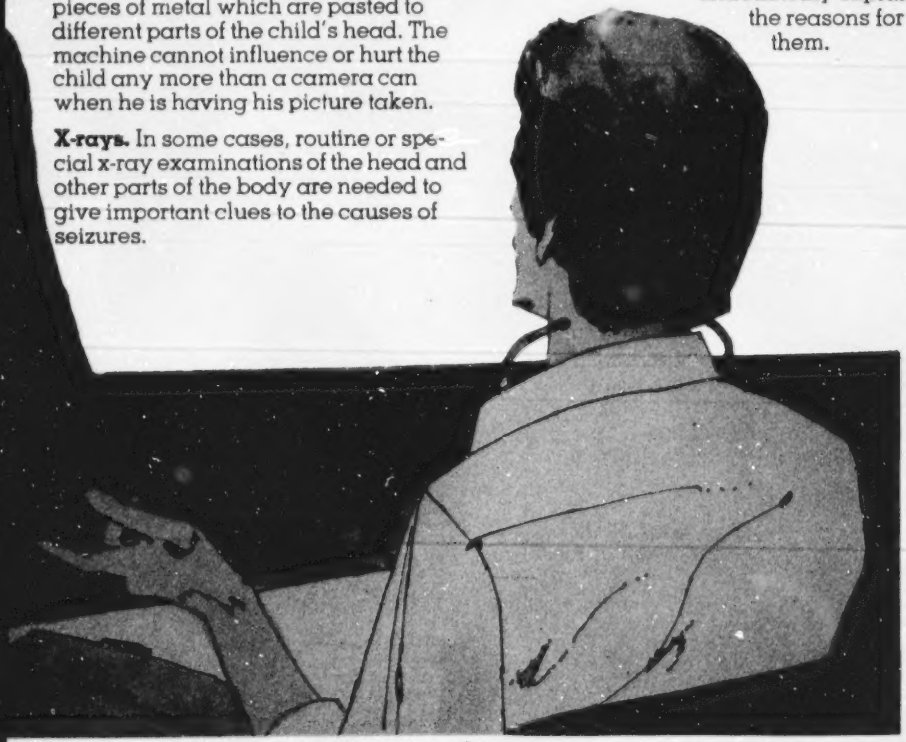
Physical examination. Besides giving your child a general physical examination, the doctor may also have a special examination made of the nervous system. This is a very detailed examination of hearing, eyesight, reflexes, muscle strength, and ability to appreciate sensation which gives valuable information about your child's seizures.

Electroencephalogram (EEG). Brain cells give off tiny amounts of electricity that can be recorded on paper by means of a machine called the electroencephalograph. This electrical activity is commonly spoken of as brain waves. If any brain cells are injured, overactive, or capable of overactivity, the EEG often shows unusual electrical waves that indicate the nature and location of the abnormality, which helps the physician select the proper treatment. This is a completely painless examination. Wires attached to the EEG machine have at their ends small pieces of metal which are pasted to different parts of the child's head. The machine cannot influence or hurt the child any more than a camera can when he is having his picture taken.

X-rays. In some cases, routine or special x-ray examinations of the head and other parts of the body are needed to give important clues to the causes of seizures.

Blood and urine examinations. These are performed, if necessary, to discover if your child has any illness outside of the brain that might be responsible for his seizures.

Additional tests. Depending on the nature of your child's seizures and what the doctor finds out from the initial diagnostic workup, additional tests may be useful. These may include special x-ray studies, eyesight and hearing tests, and more extensive blood and urine tests. Whenever these or other additional studies are needed, your doctor will undoubtedly explain the reasons for them.



How seizures are treated

The object of treatment is to totally prevent seizures from occurring. Sometimes it is necessary to settle at least temporarily for making them less severe and less frequent. Medicines called anticonvulsants are the principal treatment. As soon as the type of seizure your child has is determined, the doctor will start your child on an anticonvulsant that has proved most successful in controlling this particular kind of seizure. Since no two patients respond in exactly the same way, the doctor will plan the medication program to suit your child's individual need. The doctor will probably increase the dose until seizures are controlled or until the child is taking as much medication as he can tolerate. In many instances, a combination of medicines is more effective than one. The doctor may require blood tests from time to time to determine the amount of anticonvulsant in your child. This is very helpful in deciding whether the dosage of the medication needs to be increased, decreased, or kept the same.

Medication must be given EXACTLY as prescribed. Medicines must be given to your child in the exact amount required and at the proper times of day. No dose should ever be skipped. Unless your child gets his medication exactly as prescribed, the doctor won't know whether or not the drug is really working. Taking the medication at the right times is important in order to maintain the drugs at a constant level in the body. The sole purpose of anticonvulsants is to control your child's seizures. Usually, the drugs used for seizure control do not interfere with or affect other medicines the child may have to take for colds, sore throats, or other illnesses, but they sometimes do, and you should check with the doctor when other medications are to be used.

Never stop or change medication without advice. If you ever feel that your child's anticonvulsant medicine should be reduced or stopped, contact your doctor. If he believes there should be a change in the amount of medication or in the frequency with which it is taken, the doctor will explain what to do and how to do it. You should never discontinue, decrease, or increase the dosage of anticonvulsant medicine without first consulting your physician. Always have enough medicine on hand to avoid running out of it, especially on weekends and holidays.

If your child has reactions to his medicine. Any effective medicine may cause unpleasant or undesirable side effects. Anticonvulsants are no exception. You should always report any unusual reactions so that the doctor can decide what should be done. Often side effects clear up in time—or disappear when the doctor makes necessary adjustments in dosage.

A few medicines sometimes produce serious reactions. Nevertheless, they may be needed if other anticonvulsants fail to control seizures. If your child should require such medication, your doctor will be sure to watch out for any serious side effects by making appropriate blood and urine tests periodically. The doctor will also tell you what signs to watch out for.

A word about surgery. Most seizures can be controlled with anticonvulsants. However, sometimes seizures arise from previously injured localized areas of the brain. In such cases surgical removal of the area may eliminate seizures, or may make the seizures controllable with medication.

What you should know about seizures and their management

A grand mal seizure is often very frightening when witnessed for the first time. The fear is at least partly due to a feeling of helplessness. It may help to keep in mind that, although convulsions may resemble movements children make when they are in pain, convulsive movements during a seizure are *not* painful. Moreover, a convulsion is usually over in a few minutes.

An epileptic emergency. While most seizures are over rather quickly, a rare condition known as status epilepticus may occur. This is a series of convulsions, with each successive one beginning before the individual has fully recovered consciousness from the preceding attack. This seldom happens while a child is taking the adequate dosage of medication. But if it should, take your child to a hospital immediately because prolonged status epilepticus may produce brain damage and can be life-threatening. While it is a serious emergency, it can usually be successfully treated in the hospital.

How you can protect your child from accidental injury

A single grand mal or generalized major seizure is usually harmless unless the child injures himself in falling or hitting a sharp object. If your child has a warning or aura that he can tell you about or which you can recognize, you may have time to place him where he cannot fall or hurt himself during the convulsion. You can place him on a bed, a soft rug, or a pad on the floor. If the child himself recognizes a warning aura and understands its significance, he should be taught to lie down in a safe place whenever he experiences the sensation. If a convulsion occurs in the street, lower the child gently to the pavement and put a coat under his head. Whenever and wherever a convulsion occurs, here are some things you should and should not do.

1. Loosen all tight clothing, especially around the neck.
2. Wipe away froth or saliva from the mouth; this allows the child to breathe more easily.
3. If possible, a soft object too big to swallow should be inserted between the teeth to prevent the tongue and cheeks from being bitten. Useful objects are a rolled handkerchief or a well-padded tongue depressor.
4. DO NOT insert a hard object, such as a spoon, into the mouth; this may damage the child's teeth.
5. DO NOT try to pry the mouth open once it is tightly closed as this may also damage the teeth.
6. DO NOT put your fingers into the child's mouth; because they may be bitten.
7. DO NOT hold the child down or restrain him in any way; restraint will only tend to make movements more violent, resulting in strained and wrenched muscles.
8. When the child awakens after a seizure, reassure him about where he is and explain that everything is all right. This is important because the child will have no memory of what has happened and may be frightened.

If your child has convulsions associated with fever (so-called "febrile convulsions"), contact your doctor. Febrile convulsions are most likely to occur in infants.

How you can help your child

First help yourself. One question which immediately comes to the minds of parents with an epileptic child is: "Whose fault is it?" The truth of the matter is that epilepsy is nobody's fault. Epilepsy is not hereditary—although it tends to occur more often in some families, like diabetes or high blood pressure. The risk of having an epileptic child is greater if both parents are epileptic—especially if there is a history of the disease in the two families. It is important to face, discuss, and get rid of any guilty or accusative attitudes if you are to help your child.

Reassurance and practical precautions. Your manner and attitude are very important. If you are calm and matter-of-fact in handling seizures, your child will react with the least possible alarm and fear. After a seizure is over, the child is often confused and embarrassed. It is best to assure him that all is well. Reasonable precautions should be taken to ensure the child's safety, but these should not be severe enough to make the child feel different from other children. He should be kept away from high and dangerous places where a seizure might lead to a serious fall or injury. Whenever the child goes swimming, he should always be under the constant watchful eye of an experienced and responsible swimmer. Bicycling in city streets should be avoided. Don't give your child sharp toys to play with. No pillows should be kept in the bed of infants or very small children because they might roll over on their faces during a seizure. Never leave a small child alone on the toilet or in the bath.

Day-to-day care. Apart from the necessary precautions, treat your child as a normal child. The child should be allowed to be as active mentally and physically as any child of the same age. The usual discipline and understanding any child needs can actually help in the overall control of seizures.

What about schooling? If possible, your child should go to public school and, if permitted, take part in sports and activities. Regular physical activity and proper study habits will not bring on seizures. In fact, such activities tend to lessen the frequency of attacks. Teachers should be told about your child's condition, and instructed on how to handle seizures, and how to enlist the cooperation of schoolmates, should an attack occur in class. It is also wise to keep a change of clothing at school in case the child soils himself during a seizure.

Growing up with epilepsy. When seizures occur away from home, all children need special reassurance and this is particularly true for the older child. You can promote a healthier adjustment to seizures in the older child by giving him the responsibility for taking his own medication—as long as you can check on him without being obvious.

How to handle special problems. Despite your best efforts, difficulties may arise between you and your child that seem beyond your ability to handle. Problems may arise at any age, but they may become intensified when the child becomes a teenager, which is always a difficult period regardless of whether seizures are a factor. Your child's behavior may be more and more troublesome and difficult to

understand because he is unable to adjust emotionally to his seizures. Apart from causing tension in the family, social and emotional difficulties interfere with good seizure control. You should discuss such understandable and often unavoidable problems with your doctor. Local chapters or the national office of the Epilepsy Foundation of America can also be a source of information and guidance.

Relation of seizures to emotional and behavior problems. In a child with seizures, emotional disturbances or difficult behavior are not usually due to the seizures themselves. The problems may be related to the child's normal development or to difficulties that seizures create in his adjustment to everyday living. Knowing that he has seizures in which he loses consciousness and wakes up confused, sore, and tired without knowing what he may have done, can affect the child's attitude and behavior and make him feel inferior.

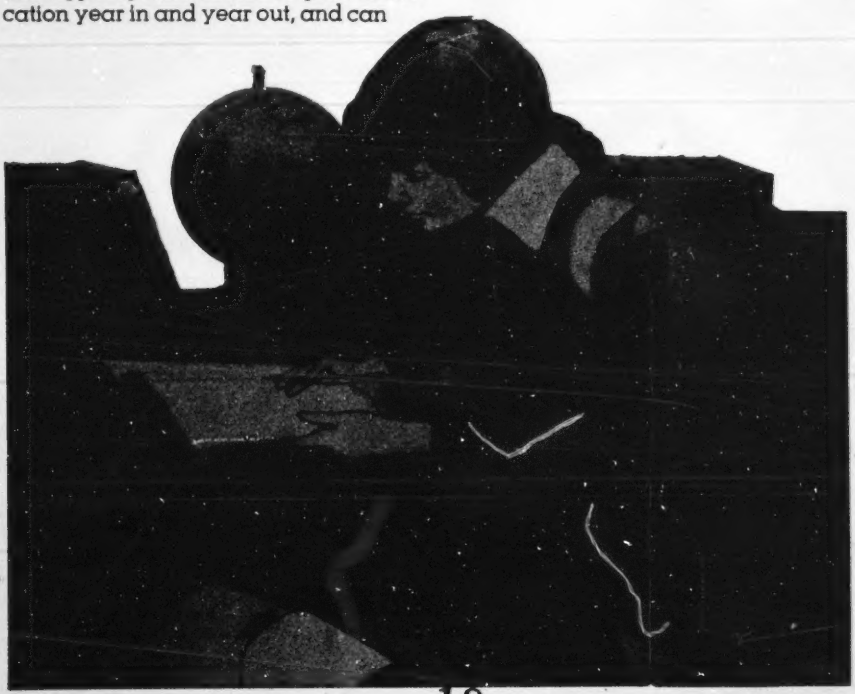
The child is also affected by the way his brothers, sisters, playmates, or schoolmates may feel about his seizures. People have some strange and misinformed ideas about epilepsy, and if they happen to be teachers, relatives, neighbors, or friends, the child may be subjected to unjustified ridicule or avoidance. Under such circumstances the child can't help feeling insecure or resentful and may develop behavior and emotional difficulties. Much can be accomplished when you understand the child's problems and help him adjust to his more difficult place in society.

Epilepsy and the retarded child. Most children with seizures are of average or above average intelligence. However, some are handicapped by difficulties in intellectual function which are the result of previous brain damage. The brain damage is the cause of both the seizures and the mental retardation. It is important to realize that the seizures themselves have not produced the retardation. The children are not retarded because they have epilepsy—they are retarded because they have brain damage which has also caused their epilepsy. Depending on the degree of impairment, retarded children require special care and understanding. In addition to learning difficulties, there may be poor performance in very specific functions. There probably are special schools and programs available in your community or state that provide special training that can help you care for your child.

What does the future hold for your child?

At the present time, seizures can be controlled or completely eliminated in most children and adults with epilepsy. With continuous treatment, seizures decrease in severity and frequency, and sometimes disappear entirely in some children as they grow older. If your child's seizures are controlled with medication, he must keep taking anticonvulsants until he has been free from seizures for at least several years before the doctor will consider reducing drug treatment. Some children have to remain on medication for many years. People with diabetes and hypothyroidism also require medication year in and year out, and can live long and useful lives. Your child may have to take medicine every day to avoid seizures—just as you have to eat to avoid starvation.

The epileptic's place in society. Most of the problems your child will have to deal with are related to our society. In some areas, schooling may be a problem. It is of great importance that children with epilepsy who meet standard requirements be given the same education as other children. If your child has special education needs, the Departments of Education and Health in



each state can inform you of available programs. When they reach the eligible age, most individuals with epilepsy want to drive automobiles. Depending on state regulations and on how well their seizures are controlled, epileptics may be able to obtain a driver's license. Employment can be difficult because of increased accident liability should a seizure occur on certain kinds of jobs. However, many large companies employ people with epilepsy and have found that serious accidents are seldom a problem. Generally a person with epilepsy is as safe a risk as anyone else and usually a better worker because of his good motivation. Unfortunately, this is not generally realized, but as problems facing people with seizures are becoming better understood, many antiquated ideas are being discarded. Naturally, epileptics should be guided into positions in which there is a minimal chance of injuring themselves or others should a seizure occur.

A good deal of thought must be given as to how the child will eventually earn a living. He should be channeled into educational courses leading toward employment that promises the best possible future.

Important points to remember

1. Be sure your child receives the proper doses of his medicine every day exactly as prescribed by the doctor.
2. Record the occurrence of every seizure, what it was like, and what time of day or night it occurred.
3. Report all reactions or unusual symptoms your child may develop while he is on medication.
4. When possible, avoid situations that tend to bring on seizures. If they cannot be avoided, advise the doctor of the circumstances under which they occurred so that he may better evaluate the effect of medication, and decide whether or not a change is needed.
5. Do not hesitate to ask for help in solving problems related to the child's behavior, schooling, home situation, or any other aspect of his or her life.

For further information.

National organizations that will supply further information concerning the problem of epilepsy are:

Epilepsy Foundation of America
1828 L Street, N.W., Suite 406
Washington, D.C. 20036

20

National Epilepsy League
6 North Michigan Avenue
Chicago, Illinois 60602